“LEARNING TO SAY GOOD-BYE”

Where can I go to get help for someone who is facing a terminal illness?

A SEMINAR FOR FAITH-BASED LEADERS

CONFERENCE REPORT

SPONSORED BY

RI COUNCIL OF CHURCHES

"Spirituality is essential to healthcare and not an amenity."

Puchalski, Anderson, Lo et al
AAMC Ethics Report 2006

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Appreciation

The RI Council of Churches and the Attorney General Task Force to Improve End of Life Care acknowledge the generous support for both the Seminar and Resource Kits:

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Patrick C. Lynch, Attorney General

PREFACE

June 26, 2007

On behalf of the Attorney General Task Force to Improve End of Life Care, I am pleased to join with the Rhode Island Council of Churches and many other groups to present this report summarizing "'**LEARNING TO SAY GOOD-BYE,' A SEMINAR FOR FAITH-BASED LEADERS**."

The end of life can be an emotional and turbulent time both for the individual and for his or her loved ones. Frequently, they seek advice and counsel from their faith-based leader, whose role is unique in comforting those who are confronting death and their loved ones. This program provided an opportunity to offer faith-based leaders information about end of life care in Rhode Island and Resource Kit.

I am grateful to the co-sponsors of the program and to the presenters. The speakers provided important information about end of life care that may help faith-based leaders counsel and advise persons who are terminally ill and their loved ones. I would like to specially thank Jack Biddick and the Allied Group for printing the Resource Kits, The Rhode Island Foundation for its support, and Reverend Dr. Donald C. Anderson and Maureen G. Glynn for organizing the program and this report.

We hope that this report will assist faith-based leaders. Together we can improve end of life care for Rhode Islanders.

Sincerely yours,

Patrick C. Lynch
Attorney General

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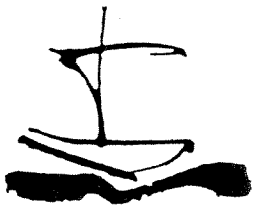

June 22, 2007

Learning to Say Good-Bye marked an important step forward in the effort to bring faith leaders and other professionals who deal with terminally ill individuals and their families into a more mutually beneficial relationship. The existing gap between the preparation provided for most faith leaders and the information needed to provide excellent end of life care is significant. Medical advances have out paced the philosophical, moral and theological questions that these advances have created.

Learning to Say Good-Bye benefited participants and planners in the following ways:

- Faith leaders gained
  - new insights into medical advances as they relate to end of life issues and the emerging discipline of palliative care
  - new information related to pain management, health care settings and specific programs, such as Comfort One
  - resources that can be used in local ministries
- Other professionals
  - gained new insights into the issues faced by faith leaders providing pastoral care to terminally ill individuals and their families
- Both groups established new or reinforced existing relationships that will help insure continuing dialogue
- Event planners
  - learned that the need for such training is even more compelling than originally anticipated
  - were gratified with the response of participants in terms of their appreciation for the training and their eagerness to continue to expand their understandings of end of life issues.

Learning to Say Good-Bye provided the Rhode Island State Council of Churches with the opportunity to provide training for faith leaders that will enrich their ministries. The council, its members and faith leaders from other faith traditions will also continue to benefit from the relationships that were established in the planning and execution of this event.

Sincerely,

Rev. Dr. Donald C. Anderson
Executive Minister

Key Facts

Importance of Faith-Based Leaders and End of Life Care

- The majority of the U.S. population considers itself to be spiritual or religious.[1]
- Nine (9) of ten (10) people believe in God or a higher power.[2]
- Among adults who face illness, 95% believe in God.[3]
- Spirituality and religion may be important for those facing illness and death.[4]
- Religious and spiritual perspectives and resources may impact a patient's understanding of end-of-life decision-making.[5]
- The end of life process can be a spiritual journey for patients and their loved ones.[6]
- The spiritual consequences of untreated pain may be increased suffering, religious needs change, a search for meaning, and inner resources weakened.[7]
- Members of the clergy bring an important, in fact critical, dimension of care to the bedside. They know the patient, the family and their values.[8,9]
- Members of the clergy are also often invited to serve as part of the hospital's biomedical ethics committee.[8]

Culture of Healthcare

- The modern hospital can be a frighteningly complex and intimidating environment.[8]
- Typical treatment in a hospital may include physicians, nurses, physician assistants, nurse aides, physical, occupational and speech therapists, social workers and discharge planners, as well as, personnel for patient transportation, housekeeping, physical plant maintenance and, of course, volunteers.[8]
- The hospital biomedical ethics committee is a multidisciplinary group of healthcare providers, often a trained biomedical ethicist, and members of the clergy, a resource that can be accessed to help resolve these dilemmas.[8]

Science of End-Life-Care

- Technology has allowed patients to recover from life-threatening illnesses but may provide limited or no benefit to a terminally ill patient.[10]

- Cardiopulmonary Resuscitation (CPR), mechanical ventilation, and artificial nutrition and hydration are examples of interventions that patients and families may need to consider in the final weeks of life.[9]

- CPR is rarely effective in patients with advanced cancer, or other advanced chronic medical conditions.[9]

- Mechanical ventilation allows critically ill patients to survive until they can again breathe on their own; however, it is rarely effective in patients with advanced cancer or other advanced chronic medical conditions.[9]

- Feeding tubes provide nutrition to patients who are unable to swallow.[9]

- The final weeks of life present very distressing decisions to patients and families.[9]

Pain Management

- Under-treatment of pain is an important public health problem.[11]

- Pain causes needless suffering.[7]

- 70% – 90% of patients with advanced disease have pain.[7]

- 40% of cancer patients have daily pain.[7]

- Opioids are an effective and established treatment for moderate to severe pain.[7]

- Non-pharmacological measures are equally important, should always be used along with medication and often can decrease the amount of medication needed.[7]

- The physical consequences of untreated pain may be fatigue, decreased movement, poor appetite, nausea, altered sleep and/or altered immune status.[7]

- The emotional consequences of untreated pain may be diminished enjoyment, anxiety, loss of control, difficulty concentrating, agitation/irritability/anger, fear, suicidal ideation and depression.[7]

- There are many myths about pain[7], including the following:

    - the confused person does not feel pain,
    - morphine use will lead to addiction,
    - pain is inevitable and untreatable in end stage, and,
    - pain and suffering are deserved for past indiscretions.

Advanced Care Planning

- Rhode Island General Laws recognize that "[a]dult persons have the fundamental right to control their decisions relating to rendering of their own medical care."[10]

- Two (2) legal ways that permit an adult person to express their desire for medical treatment are the Durable Power of Attorney for Health Care Act and the Right of Terminally Ill Act.[10,11,12]

- The Durable Power of Attorney for Health Care Act permits an adult to appoint an agent to make health care decisions when the individual is unable to make them.[12]

- Right of Terminally Ill Act, also known as a Living Will, is only effective if the individual/patient suffers a terminal condition, which means an incurable or irreversible condition that, without life sustaining procedures, will result in death and the individual is unable to communicate their wishes for medical treatment to an unattended physician.[12]

- A living will is limited to the withholding or withdrawing of life sustaining procedures and/or artificial nutrition and pain management.[12]

Comfort One Program

- Physician or designee may enroll a terminally ill patient in the Rhode Island Department of Health's Comfort One Program.[13]

- Physician or designee will affix an orange bracelet to the patient, showing that the patient is enrolled in the Comfort One Program.[13]

- The Rhode Island Department of Health's Comfort One Program will notify the enrollee's first responders that he/she is enrolled in the Comfort One Program. [13]

- The Comfort One Program permits emergency medical personnel (such as first responders) to provide comfort measures but not life support for Comfort One enrollees.[13]

Philosophy of Hospice Care

- Hospice neither hastens nor postpones death.[14]

- An interdisciplinary team of physicians, nurses, social workers, a spiritual counselor, a bereavement counselor, nursing assistants and volunteers provide hospice services.[14]

- Hospice services are covered under Medicare, Medicaid or other third party payers.[14]

- Hospice providers are experts in pain and symptom management.[14]

- There are seven (7) not-for-profit hospices and two (2) for-profit hospices serving Rhode Island.[14]

The Law

- Rhode Island enacted the Pain Assessment Act in 2002 to ensure that all patients would be appropriately assessed for pain.[15]

- The Durable Power of Attorney for Health Care Act permits an adult to appoint an agent to make health care decisions when the individual is unable to make them.[10]

- The Right of Terminally Ill Act, also known as the Living Will, permits a terminally ill patient to plan for the withholding or withdrawing of life sustaining procedures and/or artificial nutrition and pain management.[11]

- Assisted suicide, including mercy killing and euthanasia, is illegal in Rhode Island.[16]

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[8] Robert S. Crausman, MD
[9] Edward Martin, MD
[10] Rhode Island General Law §23-4.10-1 et seq.
[11] Rhode Island General Law §23-4.11-1 et seq.
[12] Maureen G. Glynn, Assistant Attorney General & Healthcare Advocate
[13] Peter Leary, Chief Emergency Services, Rhode Island Department of Health
[14] Jacqueline S. Janicki, M.S., R.N., CHPH
[15] Rhode Island General Law §5-37.61-1 et seq.
[16] Rhode Island General Law §11-60-3 et seq.

CONFERENCE SUMMARY

The Attorney General Task Force to Improve End of Life care co-sponsored with the Rhode Island State Council for Churches an educational program concerning end-of-life care for faith-based leaders called "Learning to Say Good-Bye" on October 24, 2006. The program was partially funded by a grant from the Rhode Island Foundation. Other co-sponsors of the program were the Alliance for Better Long-Term Care, Blue Cross & Blue Shield of Rhode Island, Home and Hospice Care of Rhode Island, Rhode Island Department of Elderly Affairs, Rhode Island Department of Health, Salve Regina University Department of Nursing, The Allied Group, The Ministers Council of the American Baptist Church of Rhode Island, The Miriam Hospital, URI Thanatology Certificate Program, and the VNA of Rhode Island. In addition, several businesses supported this program through in-kind support. The Allied Group donated printing for the Resource Kits. AMICA Insurance Company donated the facilities. Apple A Day Films donated a portion of the video material.

The end of life can be an emotional and turbulent time both for the individual who is dying and for his or her loved ones. Even those who may not have thought of themselves as religious may seek the comfort of spirituality or religion. Frequently, terminally ill persons or their loved ones seek advice and counsel from their faith-based leader, whose role is unique in comforting those who are confronting death as well as their loved ones.

Because understanding our complex health care system and the rights of the patient can be important to assisting terminally ill individuals and their loved ones, this seminar sought to provide faith-based leaders with information and resources to assist them in those difficult times.

The seminar established four (4) goals for attendees, sets forth below:

- To assist faith based leaders with comforting terminally ill patients and their loved ones;
- To provide faith based leaders basic science knowledge concerning end of life care;
- To provide faith based leaders with an understanding of the different roles of persons within the hospital culture; and,
- To provide faith based leaders with information concerning patients' legal rights, such as advance care planning and hospice care.

The seminar provided training to faith leaders that served eleven (11) faith groups. *See* Chart 1. The faith groups served by the program were the African Methodist Episcopal Church, American Baptist Churches of Rhode Island, Episcopal Diocese of Rhode Island, Jewish, Interfaith, Islam, United Methodist Church, Native American Church, Presbyterian Church (U.S.A.), Roman Catholic Diocese of Providence, and United Church of Christ. The demographics of religious groups in Rhode Island were well represented at the program.[1]

Spirituality and religion is important to a person who is facing end-of-life. Even people who were not spiritual during their life experienced change of heart and turned to spirituality for

comfort at the end-of-life. Providing educational training concerning end-of-life care for faith leaders across such diverse religions, hopefully will improve end of life care for most.

At the beginning of the program, a pre-test was given to attendees asking them about their understanding of specific topics of the seminar:

- The role of health care providers in hospitals and nursing homes/assisted living settings,
- The medical effects of life support,
- The medical effects of a feeding tube,
- A patient's right to pain management,
- A patient's right to advance care planning including the COMFORT ONE program, and,
- The philosophy of hospice care.

At conclusion of the program, the same questions were again presented to the attendees to determine whether or not the program increased knowledge in those areas. In all topical areas, the attendees demonstrated increased knowledge that may help them minister to terminally ill persons and their families. *See* Charts 2 through 10 provide a description of the pre-test and post-test knowledge of the attendees in these areas.

The attendees were provided a Resource Kit, consisting of copies of the PowerPoint presentations, a list of local resources and national resources, legal forms, a bibliography, an Advance care Planning DVD, and a DVD concerning end of life care. The attendees were encouraged to use the Resource Kit with the members of their congregations.

[1] According to the Rhode Island Council of Churches, the breakdown of religious membership in Rhode Island is: 461 for the African Methodist Episcopal Church, 17,623 for the American Baptist Churches of Rhode Island, 18,921 for the Episcopal Diocese of Rhode Island, 6,615 for the United Methodist Church, 1,977 for the Presbyterian Church (U.S.A.), 491,639 for the Roman Catholic Diocese of Providence, and 8,634 for the United Church of Christ.

RECOMMENDATIONS

The "LEARNING TO SAY GOOD-BYE: A SEMINAR FOR FAITH-BASED LEADERS" produced recommendations for faith-based leaders to help terminally ill persons and their loved ones. The recommendation include:

- √ Encourage faith-based leaders to become knowledgeable about end of life care to serve their congregations.
- √ Plan a session(s) concerning advance care planning for members of the congregation, including a showing of the Advanced Care Directives DVD and a discussion about Advance Care Planning.
- √ Provide members of the congregation with copies of Advance Directives forms and website information where they may be obtained.
- √ Lend the Advanced Care Directives DVD to members of the congregation to view with their families.
- √ Plan a meeting to discuss the Comfort One Program and invite a speaker to talk about it.
- √ Encourage patients to seek information about pain management.
- √ Help dispel myths about pain and end of life.
- √ Work with the hospital social worker assigned to the hospitalized patient to help the patient and his/her loved ones to cope with end of life issues.
- √ Participate with the ethics committee in hospitals to help members of the congregation address end of life care.
- √ Contact a hospice organization to plan a group session concerning care options for life-threatening illness such as advance care planning, caregiver issues, and hospice care. Invite other faith groups to participate.
- √ Plan an ecumenical program with several faith groups gathered to discuss end of life care, including pain management and advance care planning.

EXECUTIVE SUMMARIES OF SPEAKERS

THE CULTURE OF HEALTHCARE

Robert S. Crausman, MD

Introduction:

The modern hospital can be a frighteningly complex and intimidating environment. Where once there were few doctors and many nurses providing care for patients and the system comprehensible and easy to navigate; now most care is provided in the context of health care teams involving many licensed professionals in a wide variety of technologically rich settings ranging from general medical and surgical wards to Special Care units for the critically ill.

The typical cast of important characters includes physicians at various level of expertise with attending physicians in both general and sub-specialty areas. The academic institutions add further complexity by having physicians in training at the medical student, intern, resident and fellow levels. Nurses can be RN, Nurse practitioners or LPN. They may be assigned to a particular patient, geographically to a particular unit or according to a function such as IV nurse placement specialists. Additionally there are Physician Assistants, nurse aides (CNA), physical, occupational and speech therapists, social workers and discharge planners as well as personnel for patient transportation, housekeeping, physical plant maintenance and of course volunteers.

Members of the clergy bring an important, in fact critical, dimension of care to the bedside. They bring knowledge of patient, family and values. They bring a sense of social and spiritual context. Clergy can provide invaluable information to the health care team. Additionally clergy can serve as a vital bridge for more effective communication between members of the health care team, the patient and family.

Various roles and designations of members of the health care team in the context of the general hospital:

The following is excerpted from a primer written by Robert Shmerling, MD of the Beth Israel Hospital for patients:

Whether in a doctor's office or in the hospital, you may have wondered who's who. If you've ever been confused about all the people coming in and out of the doctor's examination or hospital room, here's a quick rundown of who's who.

- ***Medical Student*** — Sometimes called "student doctors," medical students have not yet earned their medical degree (M.D.). These trainees have generally completed an undergraduate college or university degree and are in the midst of a four-year medical training program. During the fourth and final year, they may be called a "Sub-Intern" because in a matter of months they will graduate medical school and become interns. During some final medical school "rotations" (one or more months spent in one area of the hospital), they take on the workload and responsibilities of an intern. <u>All orders, recommendations and other professional activities of medical students must be approved by their supervisors</u>. They include Interns, Residents and Attendings (see below).

- ***House officer*** — This generic term refers to interns and residents, trainees who have completed medical school (they have their M.D.) but must complete residency training for three or more years as part of licensure requirements. Depending on the trainee's chosen area of interest, medical students apply in one of several fields, including internal medicine, radiology, surgery, pediatrics, psychiatry, neurology, obstetrics and gynecology, dermatology and anesthesia.

    - *Intern* — A trainee in the first year of residency, just after graduation from medical school. Also called "first-year residents," these physicians tend to have the longest hours. In the past, it was not unusual for them to work 100 hours or more per week and spend every third or fourth night in the hospital. In U.S. training programs, the number of hours per week has only recently been reduced to 80 hours. The internship year is also called "PGY-1," meaning "post-graduate year 1." Under direct supervision by a number of senior physicians, interns are expected to know nearly everything about the patients assigned to them; they are the first persons called by nurses and generally write all orders for all medications, tests and consultations.

    - *Junior Resident, or PGY-2* — Physician trainees in the second year of residency; they supervise interns, teach medical students and interns, and are themselves learning and becoming more independent.

    - *Senior Resident* — A physician trainee in his or her third year of residency, also called a PGY-3. They supervise interns and medical students, have an increasingly important teaching role, and are preparing themselves for independent practice, which follows this year of training for many. In some fields, such as surgery, residency continues beyond three years; in the fourth year, for example, the physician might simply be called a fourth-year surgical resident, or PGY-4.

    - *Chief Resident* — One or more residents are invited to become chief residents. They play a key teaching role within the residency program, and serve as an intermediary between the more senior physicians, hospital administration, the teaching program and the house officers.

- ***Fellow*** — For physicians who have completed the three or more years of residency and choose to pursue subspecialty training, fellowship is the next step. If you are hospitalized with a heart problem, the first cardiologist you see may actually be a "cardiology fellow."

- ***Attending*** — These are physicians who have completed their training and practice medicine independently, without required supervision. This term applies to medical doctors (M.D.) who practice internal medicine, surgery, psychiatry or any other field of medicine. Because they have completed a residency program, they are "board eligible" and if they have passed the qualifying examination, they are "board

certified."

The term "attending" is usually used in the hospital, referring to the physician of record, the one person who is ultimately responsible for a particular patient's care. But the term also applies to others who have completed their training. Examples of attending physicians include:

- *Internist* — Not to be confused with "intern," an internist is a physician who has completed a residency in internal medicine and provides medical care to adults. Often called "general doctors" or "regular doctors," they may or may not have completed additional specialty training. Internists are often "Primary-Care Doctors," or PCPs (see below).

- *Specialist* — These attending physicians have already completed a residency and have additional training in a specialty fellowship program. They may have passed a specialty certification examination (making them "board certified" in that specialty). Examples of Attendings who are medical specialists include:

    - Allergist (allergic disease)
    - Cardiologist (heart disease)
    - Endocrinologist (hormonal disorders)
    - Gastroenterologist (digestive disease)
    - Hematologist (blood disease)
    - Infectious-disease specialist
    - Oncologist (cancer)
    - Otolaryngologist (ear, nose and throat disease)
    - Nephrologist (kidney disease)
    - Neurologist (nervous system disease)
    - Pulmonologist (lung disease)
    - Rheumatologist (joint disease)

Other Health Professionals

When visiting the hospital stay you may meet a number of other health care professionals who are not physicians. These include physician assistants, nurses, nurse practitioners, nurse specialists, physical therapists, dieticians, transporters (who help move people around the hospital in wheelchairs or gurneys; previously called "orderlies"), phlebotomists (people who take samples of blood), and receptionists. Their roles will usually be clear, especially if they have introduced themselves. However, in some situations, it can be confusing, especially when their dress and behavior are similar to a physician's or medical trainee's. For example, a nurse practitioner may do many of the same things in a routine office visit that a doctor does; a nurse anesthetist may be hard to tell apart from the anesthesiologist. However, in those situations there is a clear supervisory role for the physician who is ultimately responsible for the care delivered. The physicians generally make the more complicated evaluations and decisions.

The Bottom Line

In the end, good communication goes a long way toward sorting out who's who. If you are not sure, just ask. No one that is involved in health care should be offended by a patient asking who they are and what their role is.

The Hospital Ethics Committee

Members of the clergy are also often invited to serve as part of the hospital's biomedical ethics committee. While the formation of these committees differ subtly across institutions, they all provide similar functions and satisfy similar needs.

In the course of patient care healthcare providers often encounter ethical dilemmas for which there are no easy answers. The hospital biomedical ethics committee is a resource that can be accessed to help resolve these dilemmas.

The membership is defined by hospital policies and generally includes a multidisciplinary group of healthcare providers, often a trained biomedical ethicist, and members of the clergy. These groups typically meet monthly and, more importantly, as needed!

THE SCIENCE OF END-OF LIFE CARE

Edward Martin, MD

During the early 1900's most people died following an acute illness such as pneumonia. By the end of the century less than 10% died from an acute illness. Most died of a chronic progressive disease. Many of these illnesses progress despite therapy and the advances in health care that have improved the treatment for many illnesses but also have complicated the decisions for patients and families at the end of life.

Technology has allowed patients to recover from life-threatening illnesses but may provide limited or no benefit to a terminally ill patient. Cardiopulmonary Resuscitation (CPR), Mechanical Ventilation, and Artificial Nutrition and Hydration are examples of interventions that patients and families may need to consider in the final weeks of life.

CPR. It is a rare medical show on TV that doesn't include a patient whose life is saved by CPR. The rate of success on TV is far higher than in the real world. CPR was developed to treat reversible problems in critically ill patients. It is rarely effective in patients with advanced cancer or other advanced chronic medical conditions.

Mechanical Ventilation. Mechanical ventilation allows critically ill patients to survive until they can again breathe on their own. Only a few years ago, most hospitals would not discontinue this once it was started but now patients and families may elect to discontinue mechanical ventilation just as they would other medical treatments. While initiating mechanical ventilation in a dying patient may prolong survival, some families have felt it merely prolonged the dying process.

Artificial Nutrition and Hydration. Feeding tubes provide nutrition to patients who are unable to swallow. There is no evidence, however, that patients with advanced dementia benefit from feeding tubes, whether in terms of prolonged survival or in the prevention of aspiration pneumonia and pressure ulcers. In patients with head injury, stroke or persistent vegetative state, feeding tubes may prolong survival and physicians ultimately look to the advanced directive and the family to determine what the patient would have wanted. Again, like other medical treatments, artificial nutrition and hydration can be discontinued if the patient and family believe the burdens outweigh the benefits.

The final weeks of life present very distressing decisions to patients and families. Sound information about the benefits of these options can improve decision making to improve the quality of life for terminally ill patients

MANAGING PAIN

Therese Rochon, RNP, MSN, MA

Under-treatment of pain is an important public health problem (APS 2003). More that 50 million Americans suffer from chronic pain caused by various diseases and disorders and up to 90% of those people suffer with advanced disease (Facts on Dying). Pain causes needless suffering. Negative consequences include a patient's diminished quality of life and an increased level of distress that can have enormous physiological, psychological and sociological effects on both the patient and their loved ones.

Many barriers exist in providing good pain management. Practitioners, families and patients often misunderstand medications used in the treatment of pain. In addition to a lack of understanding about the legal use of opioids, their side effects of mental confusion and personality change are especially feared. Pain, itself, however an cause these changes.

Facts that can free patients from needless worry:

- Taking medication as soon as the pain starts prevents it from getting worse.
- Pain medications rarely cause addiction unless there is a history of substance abuse. Evidence has shown that when opioids are used for pain and not pleasure, addiction does not occur.
- Most medication side effects are manageable. Generally patients will develop a tolerance to most side effects.
- Effective treatments are available to ease pain.

Numerous studies have documented significant under-treatment of pain prompting the development of clinical pain guidelines on pain by several leading medical groups. The focus of these guidelines is to insure that all patients get the appropriate assessment and management of pain. Rhode Island enacted the Pain Assessment Act in 2002 to ensure that all patients would be appropriately assessed for pain. In addition, the Intractable Pain Act of 2002 assures that when pain is diagnosed and documented in the medical record a practitioner can treat pain without fear of prosecution. Given current knowledge about effective approaches for pain management, care providers should reassure patients and their families that most pain can be eased safely and effectively.

Opioids are an effective and established treatment for moderate to severe pain. But too often, opioids are underused or withheld because of myths about their effects. When a patient has moderate to severe pain and acetaminophen or ibuprophen have been ineffective, the guidelines advocate for the use of opioids as the next step in pain management. Starting at a low dose and titrating up slowly a practitioner can find a safe and effective opioid dose for the patient.

Non-pharmacological measures are equally important, should always be used along with medication and often can decrease the amount of medication needed. An interdisciplinary approach using psycho-social and spiritual interventions such as life review, relaxation methods,

meditation, prayer, music, rituals and pastoral counseling can have a positive impact on pain management. Other alternative approaches such as physical therapy, massage, acupuncture and electric stimulation have also been shown to be effective.

Needless suffering can be eased or avoided in advanced disease.

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ADVANCE CARE DIRECTIVES

Maureen Glynn, Assistant Attorney General and Health Care Advocate

Under Rhode Island law "[a]dult persons have the fundamental right to control their decisions relating to rendering of their own medical care." Rhode Island General Law § 23-4.10-1(a). Rhode Island law provides to two (2) legal ways that permit an adult person to express their desire for medical treatment, the Durable Power of Attorney for Health Care Act and the Right of Terminally Ill Act. *See* Rhode Island General Law §§ 23-4.10-1 through 12 and 23-4.11-1 through 15, respectively.

The Durable Power of Attorney for Health Care Act permits an adult to appoint an agent to make health care decision when the individual is unable to make them. *See* Rhode Island General Law §§ 23-4.10-1 through12. A Durable Power of Attorney for Health Care can be effective for any medical condition and is not limited to terminally ill persons. Through a Durable Power of Attorney for Health Care, an adult may specify the type of medical treatment they would want including but not limiting to life sustaining, nutrition, hydration, CPR and pain management. The individual appointed as an agent has the authority to inform heath care providers about the individual's/patient's heath care, including advocating for pain management, choosing heath care providers, permitting medical treatment services, test, procedures, and withdrawal of consent for any medical treatment services test or procedures. The agent may be vested with authority to review medical record, sign releases and make decision concerning participating in research. The selection of an agent is one of the most important decisions an individual/patient can make. The agent should be someone who the individual/patient trust; someone who knows the individual/patient's values; someone who respects the individual/patient's beliefs, and someone who can be contacted if they are needed. A Durable Power of Attorney for Heath Care must be executed as required by law in order to be effective.

The Right of Terminally Ill Act is also known as the Living Will. *See* Rhode Island General Law §§ 23-4.11-1 through 50. A living will is only effective if the individual/patient suffers a terminal condition, which means an incurable, or in reverse condition that without life sustaining procedures will result in death and that the individual is unable to communicate their wishes for medical treatment to the attending physician. A living will is limited to the withholding or withdrawing of life sustaining procedures and/or artificial nutrition and pain management. A living will has limited use because it only applies in a terminal condition.

Both the Living Will and the Durable Power of Attorney for Health Care can be revoked at any time by the individual/patient. Assisted suicide, including mercy killing and euthanasia, is illegal in Rhode Island. *See* Rhode Island General Law § 11-60-3. The Durable Power of Attorney for Health Care and Living Will are available at www.riag.ri.gov.

RHODE ISLAND DEPARTMENT OF HEALTH
DIVISION OF EMS
COMFORT ONE PROGRAM

Peter Leary

The ability to honor a patient's request for humane comfort measure while avoiding resuscitation in his last minutes has been a paradox for EMS providers. The challenge has been to devise a method for EMS providers to know at the scene, **immediately and unequivocally**, when they are to withhold life-sustaining treatment. Legislation passed in 1992 protects the EMS provider honoring such a request.

To develop **COMFORT ONE**, a committee was formed in 1991 that involved representatives from the Ambulance Service Advisory Board, Rhode Island Fire Chiefs Association, Medical Society of R.I., Division of EMS, pre-hospital care providers and Emergency Physicians. Working with legislators ensured that the final outcome was a law designed to help all touched by this specific circumstance: the ability to honor a terminal patient's wishes not to be resuscitated in the event of a cardiac or respiratory arrest.

In 1992, the Rhode Island General Assembly approved amendments to Chapter 23-4.10 of the General Laws entitled "Health Care Power of Attorney" and Chapter 23-4.1 of the General Laws entitled "Rights of the Terminally Ill Act" ("Living Will"). These amendments extended legal immunity to emergency care providers complying with the wishes of a patient who has executed a Durable Power of Attorney and/or Living Will **and** has been diagnosed by a physician to have a terminal illness. These amendments also relieve pre-hospital care providers from liability when following a physician authorized Do-Not-Resuscitate (DNR) Order. The Do-Not-Resuscitate Order must be recorded in the patient's medical record. These laws authorize the Director of Health to develop a EMS-DNR orders. Under its existing authority and consistent with these laws, the Department developed appropriate EMS protocols that have been approved by the Ambulance Service Advisory Board. The Rhode Island Department of Health, Division of Emergency Medical Services is responsible for the day-to-day operation of the **COMFORT ONE** program.

The **COMFORT ONE** program represents an innovative approach to the problem of honoring a patient's Living Will, Durable Power of Attorney or DNR Order in the out-of-hospital setting. Responsibility for determining whether appropriate DNR, Living Will or Durable Power of Attorney documents are on file and whether appropriate procedures have been followed has been formally determined prior to the emergency care provider arriving at the scene. In "the field," all the emergency provider needs to know is whether or not the **COMFORT ONE** Bracelet is present or whether a DNR Order is recorded in the patient's medical record.

Overview of Hospice

Jacqueline S. Janicki, M.S., R.N., CHPN

It is important for health care providers and clergy in the community to have an understanding of the underlying principles of Hospice care, its philosophy, eligibility criteria, and barriers to service in order for them to appropriately advocate for and support those members of the community facing end of life. The foundations of Hospice care are deeply rooted in spirituality. Thus, there is a natural alignment between hospice providers and religious leaders. This presentation sought to offer participants an opportunity to gain an information base about hospice in order to assist families in making decisions consistent with their values and beliefs when facing end of life.

Hospice Providers in Rhode Island: Many people are unaware of the number of hospice programs in the state and are confused regarding choice of program. Hospice providers can assist clergy with difficult discussions about treatment options at end-of-life. Religious leaders can contact any of Rhode Island's nine hospices listed below. General hospice questions should be directed to the "Intake" or "Admissions" department; alternatively, ask for the "Chaplain" or a "Spiritual Counselor" for more specific, faith-based questions.

What is Hospice? Hospice was established as a Medicare program thirty years ago. All nine Rhode Island licensed, Medicare-certified hospice providers follow Medicare and state guidelines for hospice care. Specific services for each patient are dictated by an individualized plan of care, but basic hospice care includes:

- RN – oversight of the hospice care with emphasis on pain/symptom management
- MD – expertise in pain/symptom management; home visits as needed
- Nursing Assistant – personal care
- Social Work – emotional assistance to the patient or family, including assistance with advance directives, applications for insurance
- Volunteers for caregiver respite, companionship, support
- Chaplain or Spiritual Counselor—work with patient's clergy to provide spiritual support as needed
- Drugs – all prescription medications related to the terminal illness
- Equipment – e.g. wheelchairs, hospital bed, commode
- Bereavement and pre-bereavement counseling
- Short-term inpatient care – in a hospital, select nursing home, or hospice inpatient facility
- Short-term respite care – oversight of the patient enabling the family to have a break from care giving
- Other services as needed and as related to the terminal illness to provide comfort

PLEASE NOTE:

1) All of the above services are covered under the Hospice Medicare Benefit and most private insurance plans. *There is no cost to the patient family for these professional, pharmaceutical, and other services.*
2) Hospice spiritual care strives to be consistent with all religious beliefs and recognizes the power of a religious community during illness and bereavement. Thus, the hospice

Chaplain/Spiritual Counselor works with the patient/family's religious leader to provide spiritual comfort and caring.

Who is eligible for Hospice? Hospice was designed thirty years ago by Medicare to be a comprehensive program of services to patients with a six-month prognosis and a desire for comfort care rather than curative treatment. However, in today's world "six month prognosis" and "curative treatment" can be extremely subjective. For example, a national study of 504 patients showed that 80% of the physicians over-estimated prognosis by a factor of about five: patients with a "three month" prognosis had a median survival of *24 days*.[1] And many treatments such as certain radiation and chemotherapies are seen as primarily providing comfort rather than cure. Thus, hospices often advise the professional to ask him/herself: "Would I be surprised if this person passed away within a year?" If the answer is "Yes," it's time to call hospice. Remember – the sooner hospice is called, the sooner hospice can help.

Guide for Choosing a Hospice? Rhode Island's nine licensed, Medicare certified hospices are listed above. As in many other health care decisions, one or two hospice providers may be recommended by a physician, hospital discharge planner, or other professional, but patients/families are encouraged to explore hospice options to find the hospice that best meets their needs. Questions to ask might include:

1. Is the hospice accredited by CHAP or JCAHO? (Accreditation provides additional quality oversight.)

2. In what geographic area are most of your patients concentrated? (This might be an indication of rapid response time on nights, weekends.)

3. What is the "typical" schedule of services I might be able to expect from the nurse? The home health aide? The Social Worker? The Chaplain? (All care should be individualized according to the patient's plan of care, but questions related to "typical" care might lead to a better understanding of the staffing capabilities of the hospice.)

4. This is the care I need: XXX (e.g. pain management, assistance with bathing/dressing every day, a hospital bed, talking about this illness with my loved ones). How will you help me with this? (Specific answers as the general tone of the conversation will help you understand the nature of the agency.)

5. How do I report problems if they occur? ("Problems" should be seen by the hospice as opportunities for improvement.)

6. What differentiates you from the other hospices in the state? (Each hospice thinks it is special. Why?)

7. What type of volunteer support is available to me?

Footnote:
1. Christakis, Nicholas A., MD, Death Foretold, The University of Chicago Press, p. 67.

HOSPITAL MINISTRY

Rev. David Ricard

1. Hospital ministry is a “quiet ministry” in which listening plays a greater role than speaking.

2. Listening does not preclude encouraging, asking questions, challenging and, at times, confronting.

3. Chaplains should not be viewed as cheerleaders for God, nor should they use “God talk” as a means of escaping real issues that are voiced.

4. Above all, there is no place for being judgmental or taking away patients feelings, e.g., “You should not feel guilty.”

5. There is also a ministry to the staff that has many of the same elements as interactions with patients/families.

6. One major role of chaplains is to recognize and challenge tribalism in the institution. There is often a lack of appreciation of the role and worth of other departments.

APPENDIX

Chart 1 Distribution of Faith Groups Served

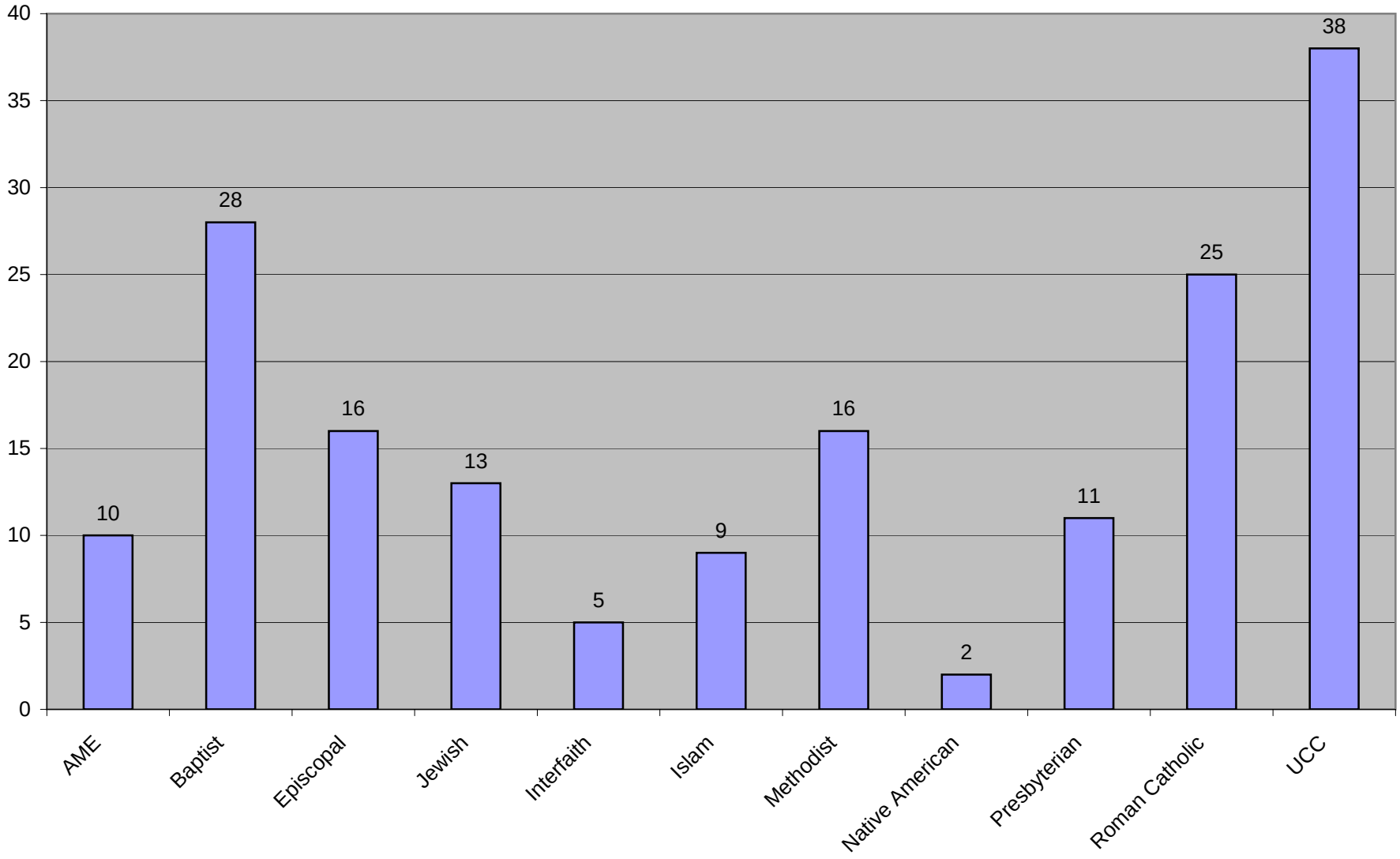
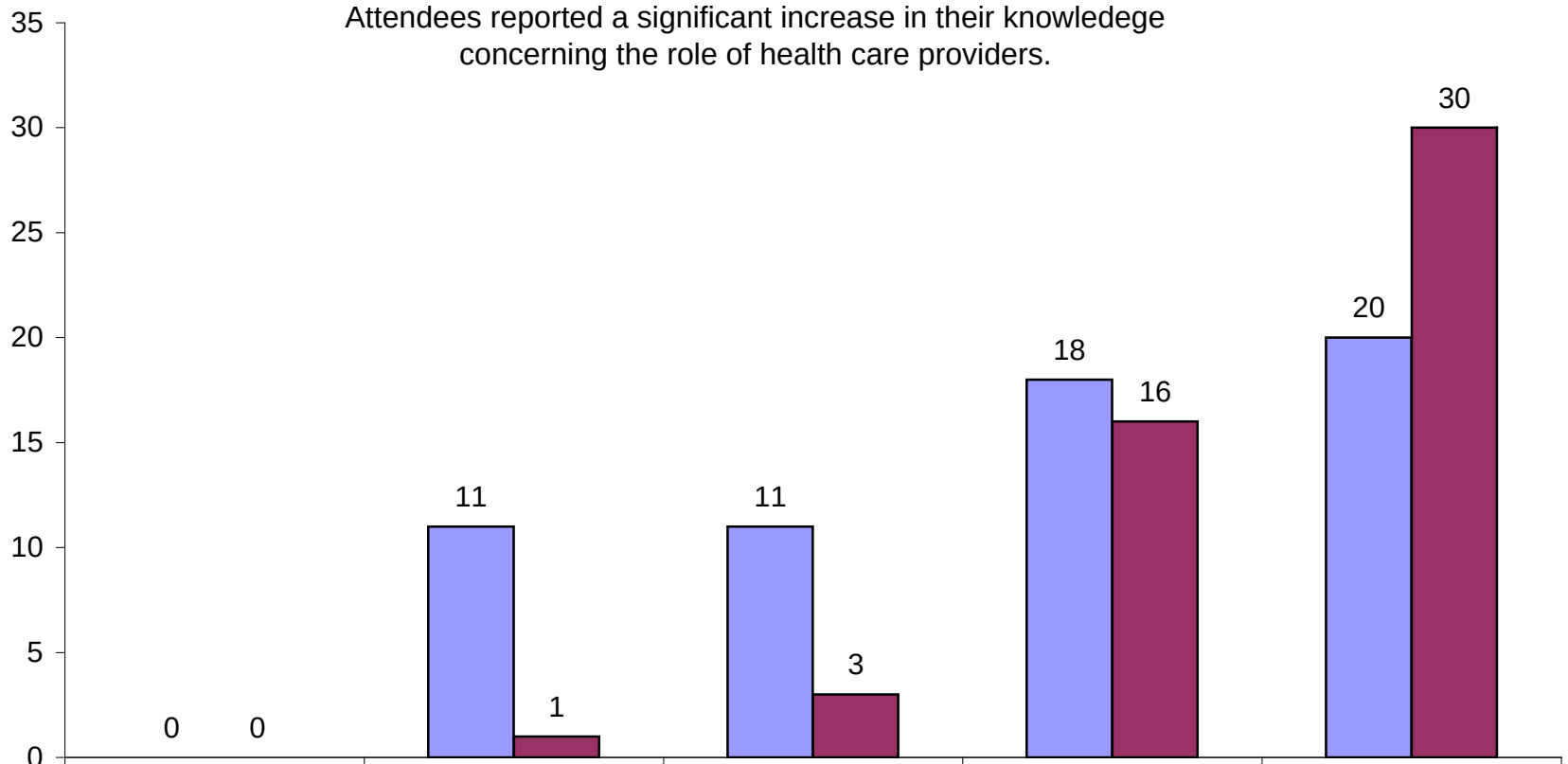


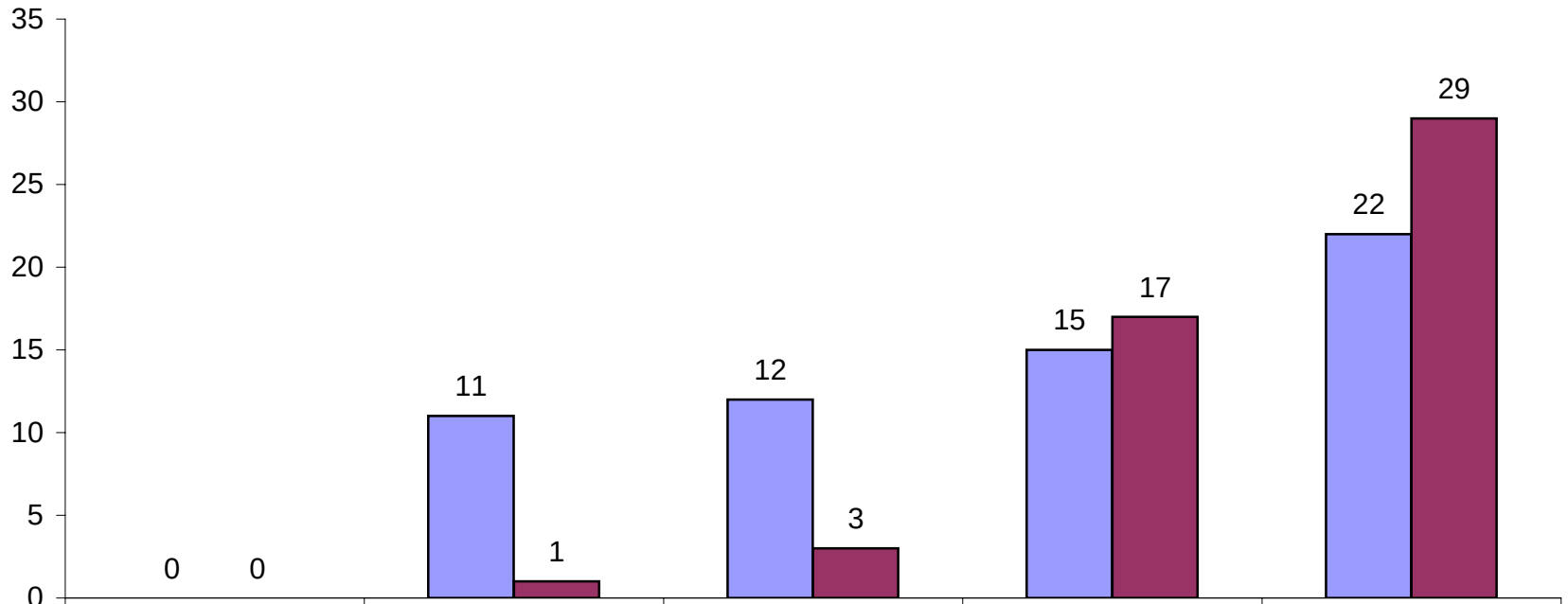
Chart 2 I understand the role of healthcare providers in hospital settings



	1 = no knowledge	2 = a little knowledge	3 = some knowledge	4 = somewhat more knowledge	5 = knowledge level sufficient to explain to congregation
Pre-Test	0	11	11	18	20
Post-Test	0	1	3	16	30

Chart 3 I understand the role of healthcare providers in the nursing home and assisted living settings

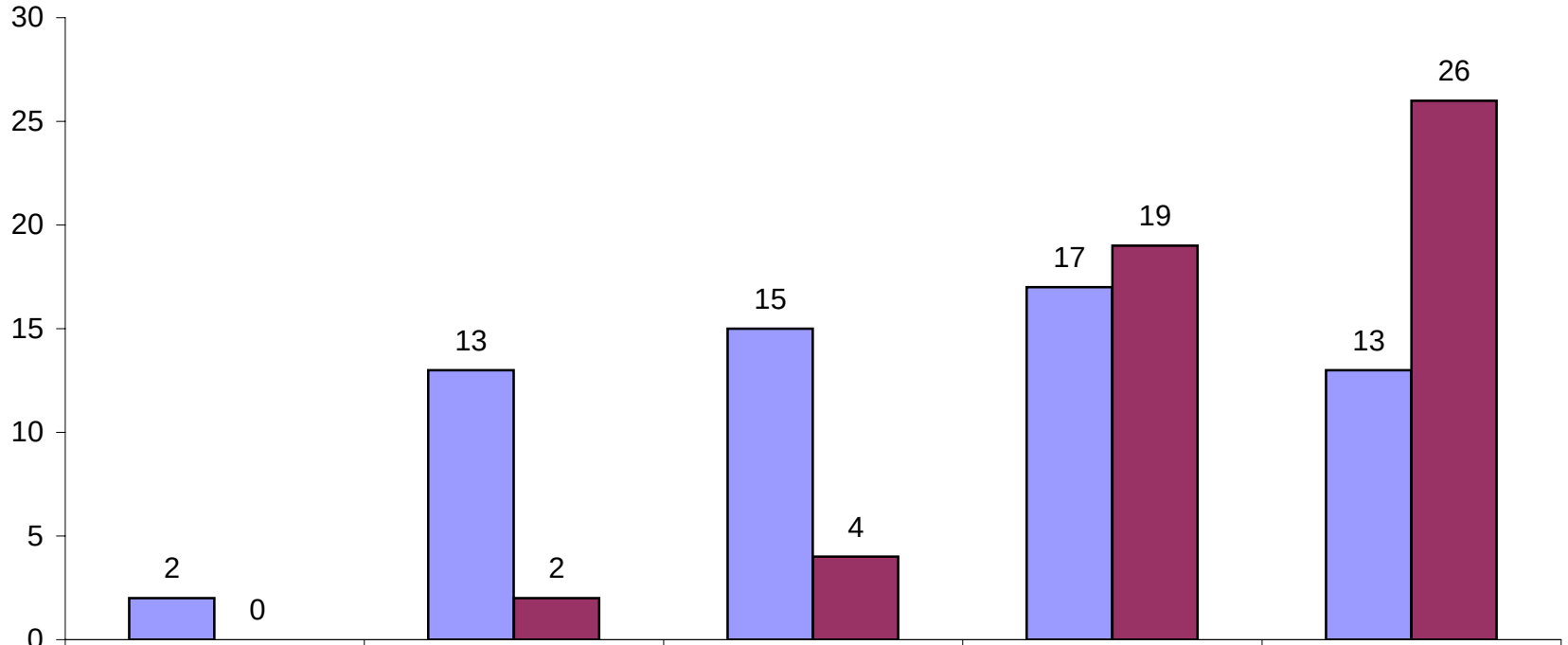
Attendees reported an increase in their knowledge concerning
the role of health care providers in nursing homes and assisted living setting.



	1 = no knowledge	2 = a little knowledge	3 = some knowledge	4 = somewhat more knowledge	5 = knowledge level sufficient to explain to congregation
Pre-Test	0	11	12	15	22
Post-Test	0	1	3	17	29

Chart 4 I understand the medical effects of life support

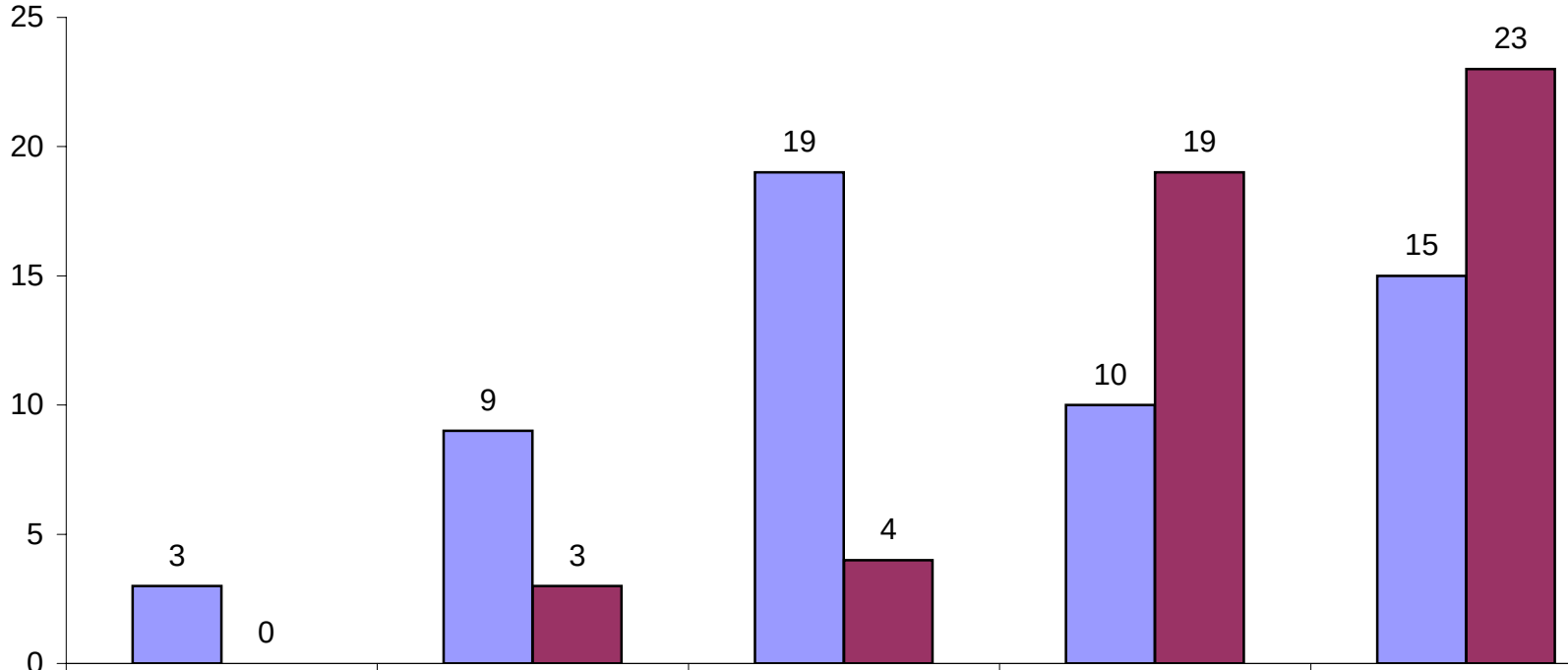
Attendees reported a significant increase concerning their knowledge of the medical effects of life support.



	1 = no knowledge	2 = a little knowledge	3 = some knowledge	4 = somewhat more knowledge	5 = knowledge level sufficient to explain to congregation
Pre-test	2	13	15	17	13
Post-Test	0	2	4	19	26

Chart 5 I understand the medical effects of a feeding tube

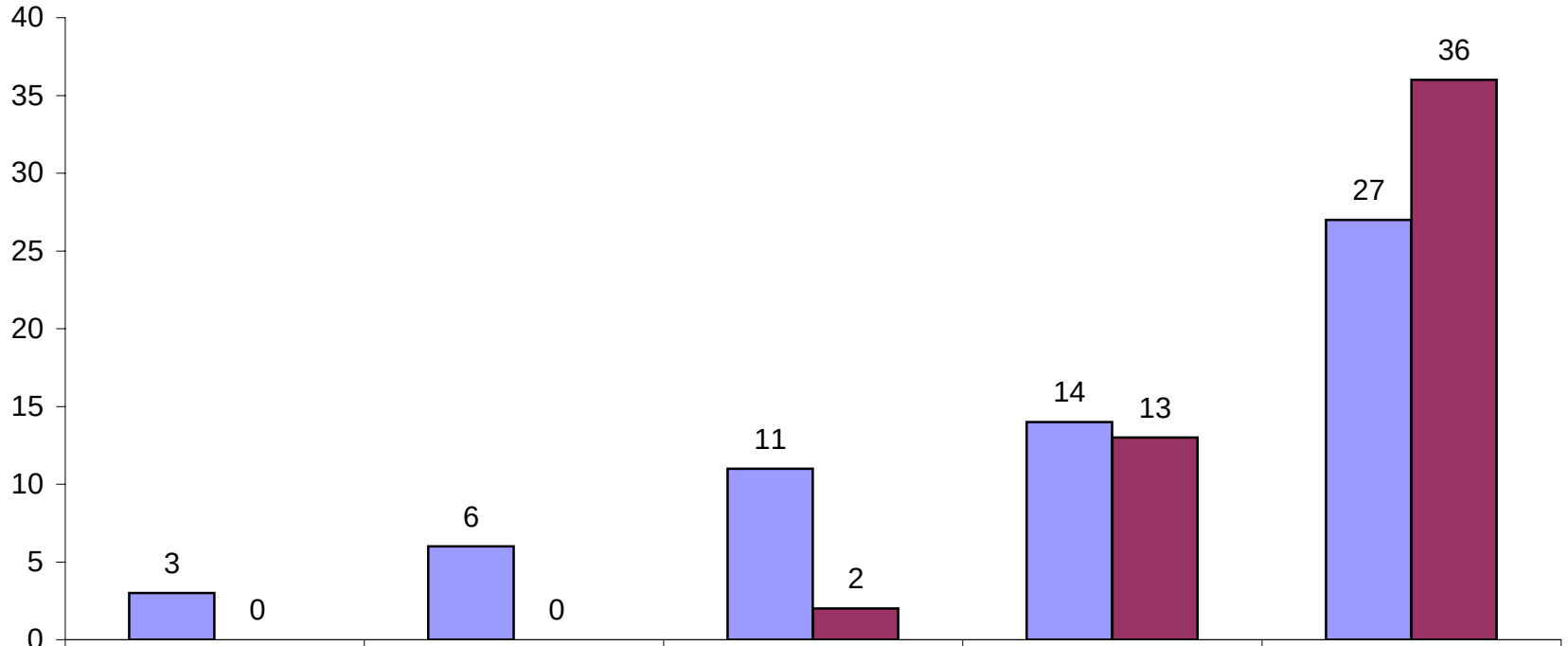
Attendees reported a significant increase concerning
their knowledge concerning the medical efects of a feeding tube.



	1 = no knowledge	2 = a little knowledge	3 = some knowledge	4 = somewhat more knowledge	5 = knowledge level sufficient to explain to congregation
Pre-Test	3	9	19	10	15
Post Test	0	3	4	19	23

Chart 6 I understand a patient's right to pain management

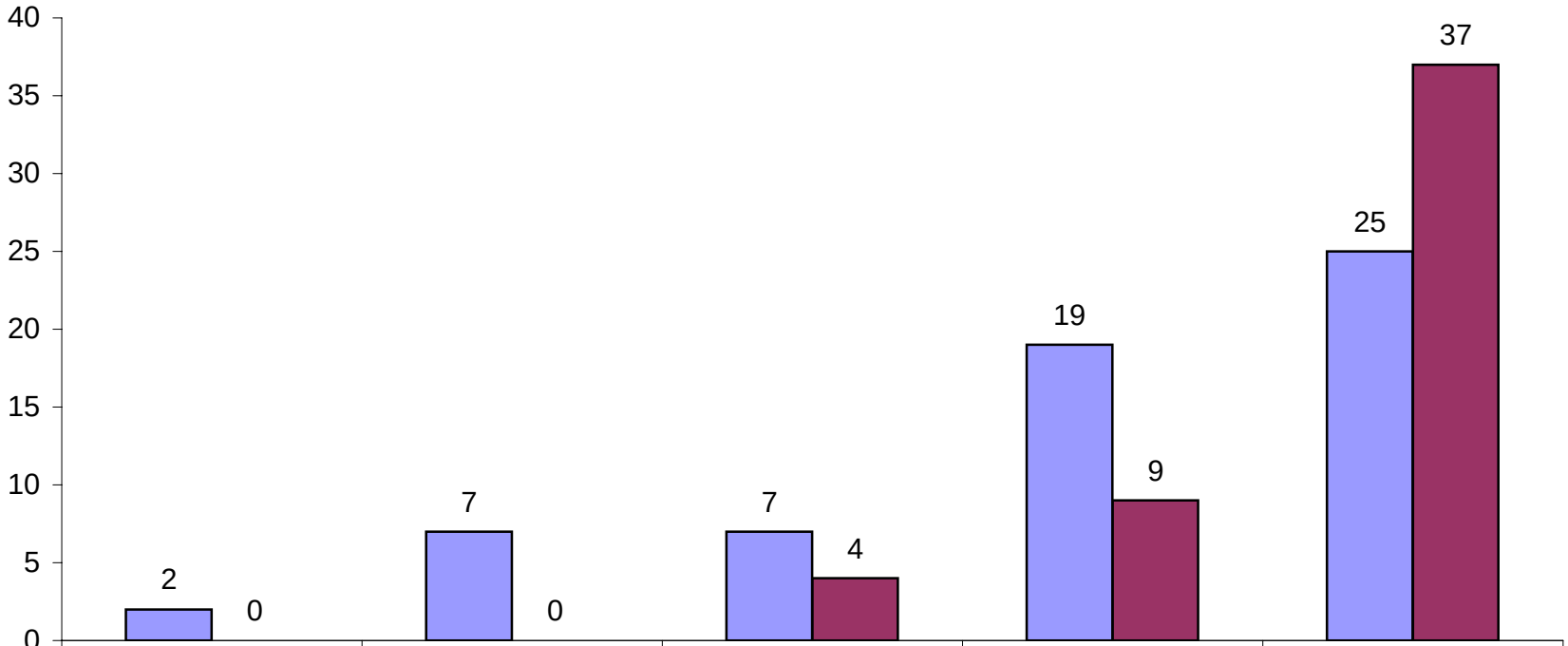
Attendees reported a significant increase in their knowledge concerning a patient's right to pain management.



	1 = no knowledge	2 = a little knowledge	3 = some knowledge	4 = somewhat more knowledge	5 = knowledge level sufficient to explain to congregation
Pre-Test	3	6	11	14	27
Post-Test	0	0	2	13	36

Chart 7 I understand a patient's right to advance care planning

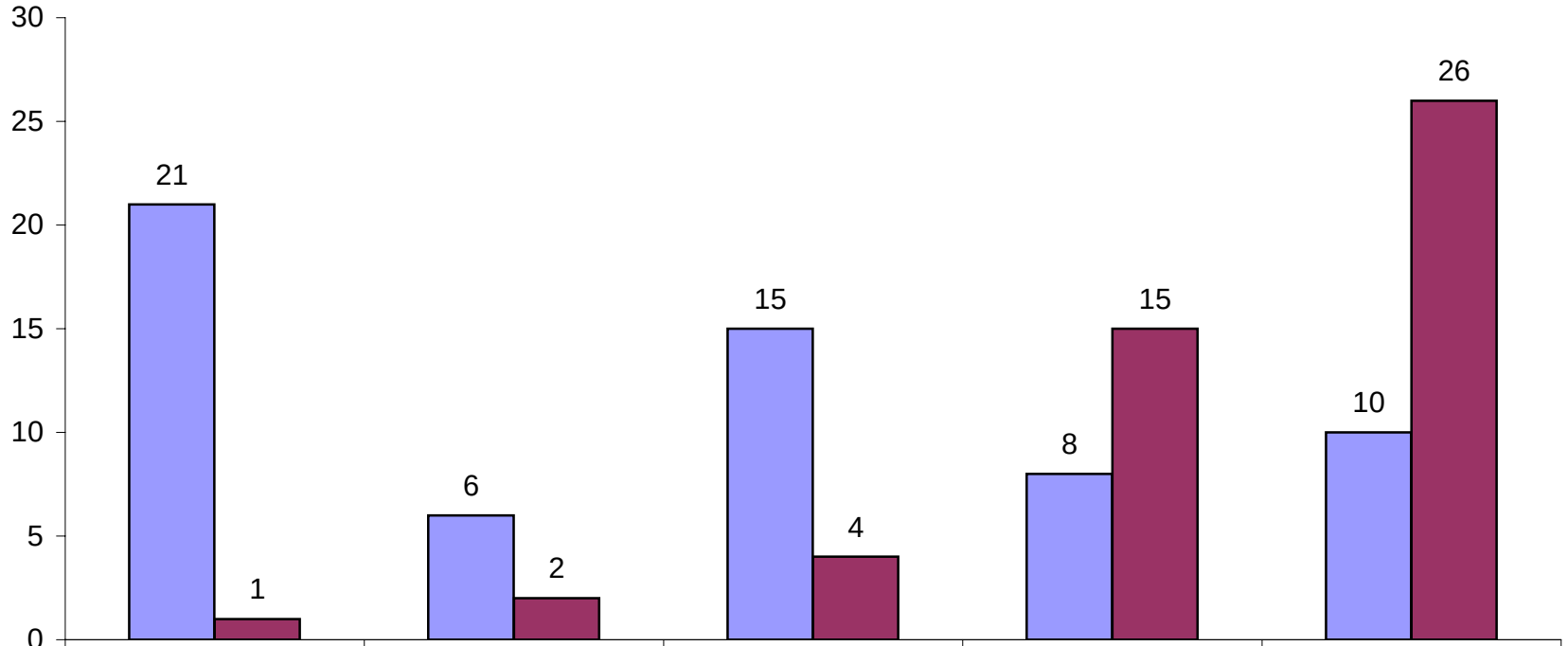
Attendees reported a very significant increase in their knowledge concerning a patient's right to advance care planning.



	1 = no knowledge	2 = a little knowledge	3 = some knowledge	4 = somewhat more knowledge	5 = knowledge level sufficient to explain to congregation
Pre-Test	2	7	7	19	25
Post-Test	0	0	4	9	37

Chart 8 I understand the Comfort One Program

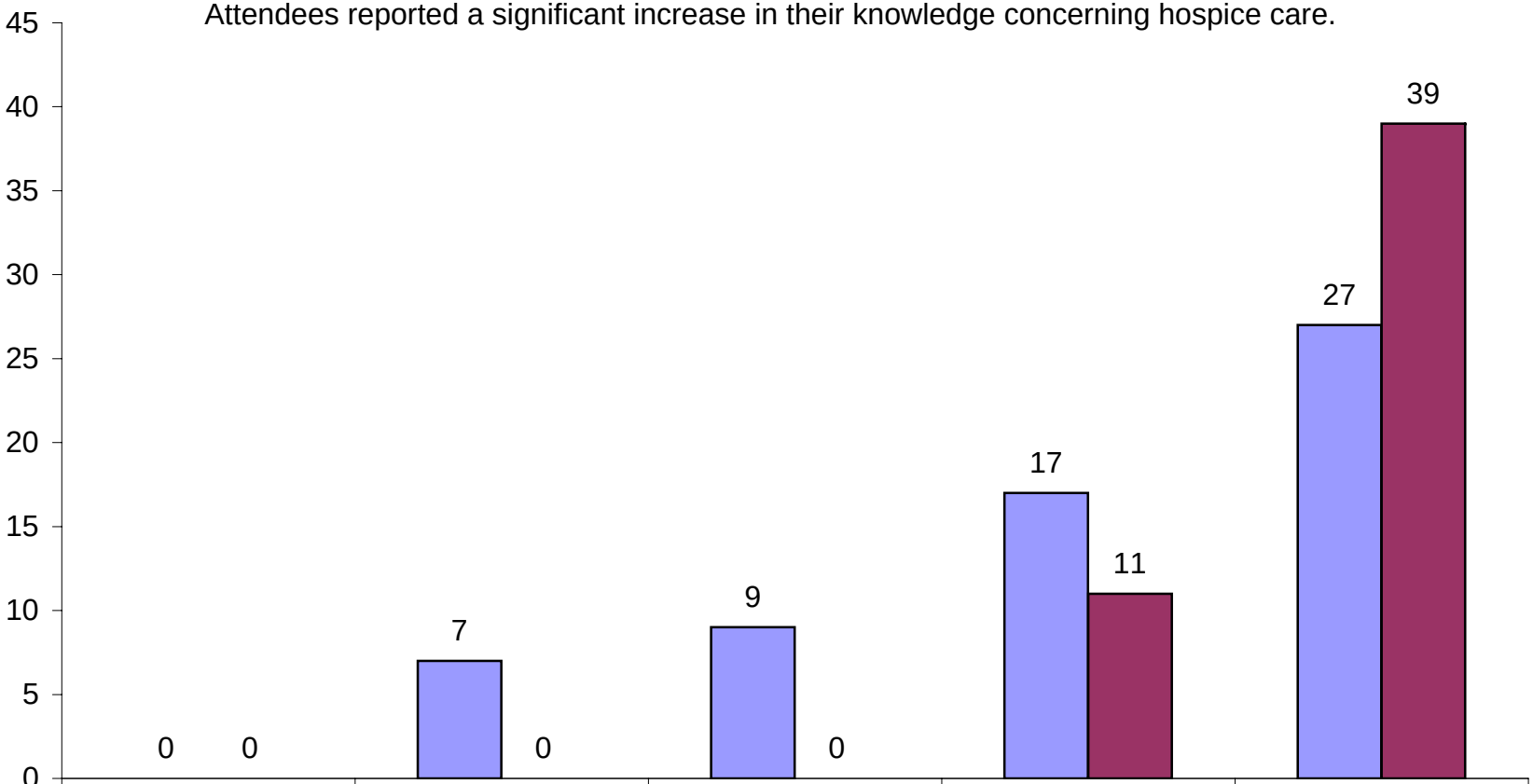
Attendees reported a very significant increase in their knowledge concerning the Comfort One Program.



	1 = no knowledge	2 = a little knowledge	3 = some knowledge	4 = somewhat more knowledge	5 = knowledge level sufficient to explain to congregation
Pre-Test	21	6	15	8	10
Post-Test	1	2	4	15	26

Chart 9 I understand the philosophy of hospice care

Attendees reported a significant increase in their knowledge concerning hospice care.



	1 = no knowledge	2 = a little knowledge	3 = some knowledge	4 = somewhat more knowledge	5 = knowledge level sufficient to explain to congregation
Pre-Test	0	7	9	17	27
Post-Test	0	0	0	11	39

Local Resources Concerning End of Life Care

- **AIDS Care Ocean State –** 18 Parkis Avenue, Providence, Rhode Island; (401) 521-3603
- **AIDS Project Rhode Island** – 232 West Exchange Street, Providence, Rhode Island; (401) 831-5522 or (800) 726-3010 (hotline)
- **Alliance for Better Long Term Care of Rhode Island** – 422 Post Road, Warwick, RI 02888; (401) 785-3340
- **Alzheimer's Association, RI Chapter** - 245 Waterman Street, Providence, Rhode Island; (401) 421-0008, (800) 244-1428 or www.alzheimers.org
- **American Cancer Society –** 931 Jefferson Boulevard, Suite 3004, Warwick, Rhode Island; (401) 243-2620 and (800) 364-5520 or www.acscan.org
- **American Heart Association, RI Chapter –** 275 Westminster Street, Providence, Rhode Island; (800) 242-8721 or www.americanheart.org
- **American Stroke Association, RI Chapter –** 275 Westminster Street, Providence, Rhode Island; (888) 4STROKE, (800) 553-6321, or www.strokeassociation.org
- **Beacon Hospice, Inc**. – 1 Catamore Blvd., East Providence, Rhode Island 02914; (401) 438-0008 and 6946 Post Road, Suite 500, North Kingstown, Rhode Island 02852; (401) 884-3845 office, (401) 884-3848 fax
- **Home & Hospice Care of Rhode Island** – 169 George Street, Pawtucket, Rhode Island; 143 Main Street, Wakefield, Rhode Island; (401) 727-7070 or (800) 338-6555, www.hhcri.org; and the Philip Hulitar Inpatient Center, 50 Maude Street, Providence, Rhode Island; (401) 351-5570
- **Hospice of Nursing Placement** – 339 East Avenue, Pawtucket, Rhode Island; (401) 453-4544
- **Hospice of VNA of Care New England** – 51 Health Lane, Warwick, Rhode Island; (401) 737-6050
- **Hospice of VNS of Greater Rhode Island** – 6 Blackstone Valley Place, Suite 515, Lincoln, Rhode Island; (401) 769-5670 or (800) 696-7991
- **Hospice of VNA of Rhode Island –** 157 Waterman Street, Providence, Rhode Island; (401) 444-9400
- **Mental Health Association of Rhode Island's Grief and Loss Collaborative –** 500 Prospect Street, Pawtucket, Rhode Island; (401) 726-2285

- **Quality Partners of Rhode Island** – 235 Promenade Street, Suite 500, Box 18, Providence, RI 02908; (401) 528-3203 or www.riqualitypartners.org

- **Respite Care Services** – 83 Stewart Street, Providence, Rhode Island; (401) 421-7886 or (800) 445-2033

- **Rhode Island Bar Association's Legal Information and Referral Service for the Elderly –** 115 Cedar Street, Providence, Rhode Island; (401) 521-5040

- **Rhode Island Department of Attorney General** – 150 South Main Street, Providence, Rhode Island 02903; (401) 274-4400 or www.riag.ri.gov

- **Rhode Island Department of Elderly Affairs** – Benjamin Rush Building 55, 35 Howard Avenue, Cranston, Rhode Island; (401) 462-4400, (401) 462-0740 (TYY) or www.dea.state.ri.us

- **Rhode Island Department of Health, Division of Facilities Regulation –** (401) 222-2566 **or** www.health.state.ri.us/hsr/facreg

- **Rhode Island Legal Services** – 56 Pine Street, Providence, Rhode Island; (401) 274-2652

- **The Borden-Carey Building – Island Office c/o Newport Hospital** – 11 Friendship Street, Newport, Rhode Island; (401) 845-1606

- **University of Rhode Island, Interdisciplinary Post-baccalaureate Certificate Program in Thanatology** – (401) 874-2766 or www.uri.edu/nursing

- **Visiting Nurse Association of Rhode Island** – 622 George Washington Highway, Lincoln, Rhode Island 02865, Phone (401) 353-2400 or Toll Free 1-800-638-6274; Fax (401) 335-9025

- **VNS of Newport and Bristol Counties Hospice** – 1184 East Main Road, Portsmouth, Rhode Island; (401) 682-2100

National Resources Concerning End Of Life Care

- **Choice in Dying, Inc.** – 1035 30th Street, NW, Washington, D.C. 20016; (202) 338-9790 or (800) 989-WILL (9455)

- **Commission on Aging with Dignity** – 7700 North Kendall Drive, Suite 602, Miami, Florida 33156; (888) 5WISHES (947437) or www.agingwithdignity.org

- **Partnership in Caring: America's Voices for the Dying** – (800) 989-9455 or www.partnershipforcaring.org

- **Advance Medical Directives: Something to think About *(Publication)*** – To order, contact **Choice in Dying**, 200 Varick Street, 10th Floor, New York, New York 10014-4810; (800) 989-WILL (9455)

- **Shape Your Health Care Future with Health Care Advance Directives (*Publication*)** – To order, call (800) 424-2277 or write **AARP-AD**, P. O. Box 51040, Washington, D.C. 20091

- **National Hospice & Palliative Care Organization**, 1700 Diagonal Road, Suite 625, Alexandria, VA 22314; 800-658-8898 or www.nhpco.org

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